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ABSTRACT

The complex special needs of families with chronically ill children will be best met through the development of regionalized systems of care. A national program is proposed in the context of a generic definition of chronic childhood illness, emphasizing coordinated regional efforts which provide services as close to a child's home as possible. The report analyzes problems and recommends improvements in organization of services, costs and financing, educational and related services, basic research, and training of health professionals. Among detailed recommendations for change in existing programs are the development of regional data systems, individual service plans, and insurance coverage options that permit financing of a broad and continuing range of services. Education-related recommendations include the adoption of more flexible policies regarding qualifying for homebound and hospital instruction. Continuing support for research is seen as a high priority, particularly in genetics, the development of new technologies, epidemiology, and family coping and adjustment. Increased attention to the problems of childhood chronic illness is needed in all health professional schools, emphasizing longitudinal experience with families of chronically ill children, collaboration among disciplines in working with families, and a broad definition of and approach to child and family needs. (JW)

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Summary of Findings and Recommendations
Public Policies Affecting Chronically Ill Children and Their Families

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Summary of Findings and Recommendations
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Center for the Study of Families and Children
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THE FOCUS OF THE INQUIRY

A systematic review of the needs of children with severe chronic illnesses is important and timely for many reasons. Chronically ill children have not received the same measure of public concern that has appropriately been afforded other groups of handicapped children and youth. Many chronically ill children who would have died young are living longer, mainly because of tremendous advances in medical care. An estimated one million children in the United States have severe chronic illnesses, and most will live at least to young adulthood. Expenditures for the care of chronically ill children constitute a major portion of the child health dollar. And while knowledge among professionals and researchers of the needs of chronically ill children has increased, public awareness and understanding have not.

The health care system, broadly defined, has not kept pace with the changing needs of severely chronically ill children and their families, nor with the increasing awareness of the importance of a broad perspective in meeting family needs.

For purposes of public policy, there are compelling arguments to consider chronically ill children as a group, rather than to define policy and programs by specific disease or condition. It is clear that there are important differences among chronic childhood illnesses--cystic fibrosis is different from diabetes or myelomeningocele--and one can classify chronic illnesses in a

number of ways, such as age of onset, impact on longevity, mobility, need for frequent hospitalization, and effects on cognitive capacities. Nevertheless there are many issues faced by chronically ill children and their families which are similar regardless of the specific condition and which in large part distinguish chronically ill children from their able-bodied contemporaries. The life experiences of children with different diseases -- for example, cystic fibrosis, juvenile diabetes, severe asthma, congenital heart disease, sickle cell disease, leukemia, spina bifida, hemophilia and muscular dystrophy -- include:

.The cost of treatment is high and often borne by families.

.Many providers are involved over an extended period of time. Treatment regimens are often complex, and at times conflicting.

.The daily burden of care, day after day and week after week, falls on the family.

.The courses of the diseases are highly unpredictable, though the very fact of chronicity creates special problems of coping for child and family. Adjustment problems can be enormous. Adjustment can be exacerbated in normally difficult periods of development, such as adolescence.

.Many chronic childhood illnesses are accompanied by pain and discomfort, sometimes beyond the appreciation of the healthy individual.

.Treatment itself is arduous, painful, and sometimes embarrassing. Non-compliance with the treatment may become a means by which

the adolescent's struggle for independence is expressed.

.The rarity of the illnesses contributes to public and professional misunderstanding, and to the educational, social and psychological isolation of children and parents.

.Parental fatigue, marital stress, low family morale, reduced career mobility, and poor adjustment of siblings are difficulties experienced by families of chronically ill children.

.The chronically ill child's school performance and social adjustment are affected by frequent absences, low energy, and need for health care while in school.

.Planning for the child's future -- for education and vocation -- raises sensitive issues.

A PROPOSAL FOR A NATIONAL REGIONALIZED PROGRAM FOR CHRONICALLY ILL CHILDREN AND THEIR FAMILIES

The complex special needs of families with chronically ill children will be met best through the development of regionalized systems of care. The systems of care should arise through a new national program, emphasizing coordinated regional efforts, providing services as close to a child's home as possible, and assuring access to all children with chronic handicapping conditions. The Vanderbilt project analyzes problems and recommends improvements in five areas of the present system: organization and financing of services, schools, professional training programs, and research efforts. From this analysis flows the project's recommendation for a new national program.

The program would establish a regionalized network of Family and Chronically Ill Child offices staffed by a core of professionals experienced in the needs of families with children who have a variety of severe chronic illnesses. For the purposes of this program, regions would be small enough that staff can be knowledgeable about a broad array of regional services and large enough to include most needed specialty services. The offices would be responsible for coordination of care, for developing Individual Enablement Plans with a defined scope of services, for assuring access to specialty services, and for communicating with schools and community agencies. The recommended program recognizes the families' central needs for coordination of care and for access to both medical and non-medical services.

The main task of the regional program offices is to assure the provision of the necessary broad group of services to families with chronically ill children. Common service needs include access to excellent, up-to-date, and technologically appropriate tertiary care as well as optimal primary care (which chronically ill children may need more than do able-bodied children), help with the major financial burdens of illness, family support concerning siblings and respite care, genetic counseling, counseling and planning concerning issues of prognosis and jobs, and counseling to aid families in developing their own coping skills to deal with the many stresses of chronic childhood illness. Some services would be provided directly by regional staff; for others staff would actively seek additional resources, both programmatic and financial. The regional programs would work to enhance and expand the role of the primary provider in working with chronically ill children, by (a) improving communication with other providers and agencies involved with the child, (b) serving as an easy source of information and referral, even for unusual problems, and (c) providing community-based continuing education. The resultant increased complexity of practice should be attractive to general pediatricians and other child health providers.

The location of the offices can vary from community to community, from establishment of free-standing, single-purpose agencies to placement in multi-purpose community organizations, tertiary care medical centers, primary care centers, or schools, to name only a few possibilities. The relative advantages of any particular organizational arrangement must be assessed carefully. Offices located in a tertiary care academic health center, as an

example, may provide easy access for the many chronically ill children who receive medical treatment in the specialty clinics; on the other hand, close ties to the sophisticated research centers increase the technological bias in care, to the relative neglect of other basic services. Location in community agencies may provide greater emphasis on family needs and community linkages; there may be disadvantages, though, in adding another layer of bureaucracy and in less successful communication with the specialty medical centers. The design of the program should emphasize the functions -- coordination of care, access to quality medical and non-medical services, and community liaison -- with the offices located to enhance achievement of program purposes.

The proposed program recognizes a generic definition of chronic childhood illness: a health condition which leads to hospitalization for more than one month in a year, or interferes with the child's functioning for more than three months in a year, or (at the time of diagnosis) is likely to do so (e.g., leukemia and certain birth defects). The program would have universal eligibility, without means testing. With relatively rare phenomena like chronic illness in a child, and where there is a need often for very specialized and scarce resources, it makes little sense to develop chronic disease programs for the public sector separate from those for the private sector -- or private and public orthopedic or myelodysplasia programs.

Financial support for the National Regionalized Program for Families with Chronically Ill Children could take various forms. One option would be full public support, either federal or by a combination of federal and state revenues. A second option is to maintain the present diversity of insurance,

both public and private. A child and family becoming eligible for the program, by meeting the generic definition of chronic illness, would then have access to the scope of services defined in the regional plan. The costs of most health services would then be borne by the original insuror. Additional public monies would be needed in three main areas: to support some essential services not payable by present insurors, to build the program's infrastructure through direct project support, and to finance insurance for the 10-25% of families without third-party coverage.

We present the project's recommendation with full knowledge of current political realities and fiscal constraints which make implementation of new programs in the short term very difficult. Nonetheless, the compelling burdens of chronically ill children and their families identified and documented in the project encourage us to take a long term view rather than to tailor recommendations to assumptions about today's possibilities.

ISSUES IN THE SYSTEM OF CARE

The health care system for chronically ill children and their families is defined broadly. The project identifies issues and problems in the main areas of the system: organization and financing of medical and non-medical services, schools and communities, research efforts and training programs.

Organization of Services

- The specialization that has improved the medical outcomes for chronically ill children has resulted, ironically, in fragmentation of medical services. The lack of coordination of services, not normally a problem in the care of children with acute illnesses, takes on serious proportions when there is severe chronic illness.
- The diverse providers who treat an individual child infrequently coordinate their efforts. Caregivers may change over the long haul of the illness and its often complex treatment. Families often lack supportive counseling in the care and management of the child with chronic illness.
- Public programs such as those supported by the Crippled Children's Service, Medicaid and the federal research agencies, provide many essential services to chronically ill children. Yet they often favor the provision of high technology services (usually at high cost) and neglect relatively the broad base of services

needed to maximize child functioning and family potential.

Costs and Financing of Services

.Children with chronic conditions, particularly those with functional disabilities, require much greater than average use of hospital and ambulatory care. In 1977, chronic conditions accounted for 36 percent of total hospital days for all children less than age 15 in the United States. Similarly children limited in activity had greatly increased use of hospitals and visited the doctor more than twice as much as other chronically ill children.

.In 1980, expenditures for physician visits and hospitalization of children with activity limitation totaled over $1.6 billion; 65% of these costs were for hospitalization. Children with the most severe limitations have the highest per child costs as well -- three times the national average for all children.

.The cost of care of children with chronic illnesses is beyond the capability of most families. Small studies found, for example, that direct medical costs for children with hemophilia averaged $10,000 in 1980, and some cases cost well over $50,000. Direct medical costs for infants with congenital heart disease were $13,000 in the first year alone. Medical costs of children with cystic fibrosis ranged as high as $20,000. These figures include neither direct non-medical costs such as transportation and telephone, nor indirect costs such as lost salaries, opportunities

foregone and diminished energies.

.Families with chronically ill children who receive SSI benefits report out-of-pocket costs as high as $1,500 per month.

.Public programs account for half of all expenditures for the care of chronically disabled children, including chronically ill children. Clearly the combined effect of simultaneous reductions in these programs -- Medicaid, Medicare and the Maternal and Child Health Block Grant (Crippled Children's Service) -- is very serious for chronically ill children.

.The distribution of payment for the medical care of chronically ill children is capricious. There is great variability of financial coverage by income, condition, severity, type of services and geography. The gaps in coverage are of several types.

-Gaps in benefits. Many programs fail to reimburse for services used frequently by chronically ill children -- transportation, social services, home care materials, and genetic counseling.

-Gaps in populations covered. 10% of all children with functional limitations have no insurance, public or private, and 20% of low income children with functional limitations are uninsured.

-Gaps in public programs. Medicaid covers only 25 percent of the disabled child population and only about 60 percent of disabled children below poverty. State variation in Medicaid eligibility and scope of coverage for disabled children is tremendous. Only

10 percent of Nevada's chronically ill children are covered compared to the District of Columbia's coverage of 50 percent. This range is even greater among low-income disabled children -- 20 percent in Nevada versus 86 percent in New York. Crippled Children's Service programs serve over a million handicapped children, at a cost of nearly $300 million. Large variations exist between CCS programs in numbers of children served, generosity of state programs and conditions eligible for treatment. The Supplemental Security Income program, another important federal program for the disabled population, covers few children; only 5% of SSI beneficiaries are children.

-Gaps in private programs. The role of private voluntary health associations in financing care for disabled children is limited to "insurors of last resort." The associations vary not only in their size but also in their distributions of expenditures for research, medical services, professional education and training, public health education and community services and advocacy.

.Many of the nation's children are not covered by private insurance, and chronically ill children are almost twice as likely as other children to lack this coverage. While private insurance does not cover 25% of all children, it does not cover 40% of disabled children.

.Exclusion from private group insurance policies occurs in a number of circumstances: employment in small firms or on a seasonal basis,

self-employment and unemployment; lack of conversion privileges to individual policies for many employees -- for those whose jobs terminate, for spouses of divorced or deceased employees, and for employees' dependent children who marry or reach the age limit under group policies; and waiting periods for pre-existing conditions.

.Competition proposals are based on an assumption of little applicability to most chronically ill children and their families: that choice is a principal determinant in the use of medical services. But for chronically ill children, this is usually not the case.

Schools and Communities

.Education serves a number of important functions in all children's lives, and its significance for children who have special problems cannot be overestimated. Many chronically ill children evidence no unusual learning problems but many require medical and physical accommodations to participate in school. Under P.L. 94-142, they need "related services" without needing "special education"; yet by definition there can be no related services without special education.

.Chronically ill children may need specialized instruction (e.g., vocational and career preparation, or even adaptive physical education, nutrition, and care of appliances) in addition to instruction in traditional academic areas. These needs are considered by many teachers and administrators to be out-

side the purview of the public schools. Professional preparation programs for handling medical matters in the classroom are unavailable for the most part.

.Teachers' attitudes regarding expectations for academic achievement by chronically ill children often result in exaggerated deference to the medical implications of a child's handicap. The teacher, the parent, and the physician may have different and sometimes incompatible goals for a chronically ill child.

.Development of plans for children with special health needs is limited too often by calling for services that are available already in a school system rather than for services the child actually needs. Costs to local education agencies, which have assumed the provider functions, are cited as a deterrent to provision of a broad range of health services that may be needed.

.A major educational problem of chronically ill children is frequent or occasional interruption in school attendance, from prolonged hospitalization, regular weekly treatments, or unpredictable three or four day absences. Current home and hospital school programs, often the only means of providing educational services to sick students, are characterized by great diversity in rules, requirements, and quality. Rigidity in absence requirements for eligibility for home programs and brief length of teacher time on a weekly basis (most states require only three

hours per week) illustrate some of the problems.

.The need for supportive services in school complicates educational placement and programming decisions for chronically ill children. Service needs may include special diets (for students with asthma, diabetes, or advanced kidney disease), physical therapy and special transportation (for students with rheumatoid arthritis), special physical handling (for students with spina bifida or muscular dystrophy), social work and liaison services, counseling, and in-school administration of medicines and treatments such as catheterization.

.Schools have limited health services for all children, and few educational authorities have developed and implemented specific policies and program health standards for children with special needs.

.Chronically ill children in school have great need for emotional support and opportunities to experience normal peer relationships. Some of the obstacles to meeting these needs include:

-erratic attendance patterns

-maladaptive social behavior

-embarrassing side effects of specific diseases

-isolation due to equipment needs or geographic location.

Perhaps the most important obstacle is the unavailability of support for parents in coping with chronic illness.

Research

.The dramatic improvements in the treatment of many chronic illnesses in the past quarter century have in large part come as a result of a sizeable investment in basic biomedical research, mainly through the National Institutes of Health. Interinstitutional studies of childhood cancers, supported by the National Cancer Institute, as an example, have reversed the prospects for many children with leukemia and other previously uniformly fatal illnesses. Similar examples abound in such areas as chronic kidney diseases, the prevention of birth defects, and the treatment of cystic fibrosis.

.Many important advances have come through collaborative research among scientists representing different biomedical disciplines, for example, physiology and biochemistry.

.Support for basic biomedical research has plateaued in the past few years, diminishing the rapid growth in new knowledge characteristic of the previous two decades.

.Greater limitations on available funding have diminished the attractiveness of research careers to many potentially excellent young investigators, and the infusion of new talent to many areas of basic research has been sharply limited.

.Support for basic research in other disciplines critical to the needs of families with chronically ill children has been far less generous. Investment in behavioral sciences research represents

a minimal percentage of the NIH effort in chronic illness. Even less support has been available in such areas as health services and nursing science research.

.For psychologists in academic health centers, as an example, it is rare that one can achieve research support, despite the pressing need to increase the understanding of basic mechanisms of psychological impact of chronic illness, the processes of coping, and the interaction of psychological matters and physiologic response to illness. Where groups of behavioral practitioners have become involved with chronic childhood illness, main support has been from direct service activities and not for the development of new knowledge.

.Careful and timely assessment of new technologies is critical to the care of children with chronic illnesses. Federal efforts in assessment have included the Office of Technology Assessment and the National Center for Health Care Technology, yet the former has paid little attention to the needs of children and the latter was dismantled not long after its creation.

.Several Federal agencies other than the NIH have variably supported research in chronic child illness, including the Office of Maternal and Child Health, the National Institute of Mental Health, and the National Center for Health Services Research and Development. These efforts have been curtailed markedly in recent years and agencies are somewhat adrift

in defining their research missions, especially as they relate to chronic childhood illness.

The Training of Providers

.Most health providers, regardless of discipline, have limited experience with chronically ill children during training. Pediatricians, health professionals with perhaps the greatest direct experience with childhood illness, are mainly exposed to the acute exacerbations of chronic conditions and only occasionally to the long-term problems and family aspects of chronic childhood illness.

.Nursing training, especially with new integrated curricula, offers little opportunity to consider chronically ill children during undergraduate years. Even in specialized graduate nursing training, opportunities for long-term supervised interaction with families with chronically ill children are very limited. Other health professionals (e.g., psychologists, nutritionists) may have even less exposure.

.Physician training emphasizes acute treatment issues, rather than long-term and family management problems, partly because reimbursement is more available for treatment than for support services. Reform in physician training will likely accompany reform of payment for health services.

.Public health practitioners provide leadership of Crippled

Children's and related programs. Yet their training is often divorced from the places where chronically ill children and their families seek health care. The separation of public health people from the clinical realm has led to some of the fragmentation of services for children and diminished the likelihood of effective public-private collaboration in program development.

.Faculties of key professional schools (e.g., medicine, nursing, psychology, social work) rarely include members whose academic focus has been the broad problems affecting families with chronically ill children. Faculties may include many disease specialists, but rarely generalists interested in chronic childhood illness, its coordination or family implications.

.Physician training especially emphasizes curing rather than caring. Yet the very fact of chronicity means that most of these conditions last indefinitely without cure.

PRINCIPLES FOR POLICY CONCERNING CARE OF CHRONICALLY ILL CHILDREN AND THEIR FAMILIES

Policy concerning chronically ill children should address the gaps between the special needs of the children and their families and the characteristics of the health care system. From consideration of the policy issues raised above, the project has identified certain basic principles which should underlie policy, regardless of specific organizational and program characteristics.

- Children with chronic illnesses and their families have special needs which merit attention, beyond that provided to the health needs of able-bodied children. Improvements in health services in general will improve the lot of chronically ill children, and policy development for chronic childhood illness should be integrated with other developments in national child health policy. Nonetheless, the special needs common to most children with chronic impairment will continue to need special attention in public policy.
- Families have the central role in caring for their own members and the goal of policy should be to enable families to carry out their responsibilities to nurture their children and encourage their most effective development.
- Services should be distributed in an equitable and just fashion, specifically excluding from the distribution formula such non-functional characteristics as race, sex and socioeconomic class.

.Policy should encourage professional services of a highly ethical nature. Key elements include truth telling, confidentiality, maintenance of dignity and respect for family preference, professionals' recognition of limits of their own effectiveness, and emphasis on collaboration.

.Chronically ill children should stay on task in school to the greatest degree possible. Schooling is the main occupation of young people, and the interference of illness and its treatment with educational activities should be diminished.

.The public commitment to sound basic research has resulted in tremendous advances in the health of chronically ill children. Policy should encourage the continuation and expansion not only of biological research, but also of psychological, biosocial and health services research related to chronic illness in childhood.

RECOMMENDATIONS FOR CHANGE IN EXISTING PROGRAMS

The project recognizes that there are paths to improved policies and programs for chronically ill children and their families with or without the adoption of the proposed Regionalized Program for Families with Chronically Ill Children. Modifications in the system of care may enable existing programs to meet more effectively the extraordinary needs of chronically ill children and their families. Recommended changes will also move the system of care and services in the direction of the recommended national program.

Organization of Services

Improved regional efforts can develop through any of a number of present structures, including state Crippled Children's agencies, the University-Affiliated Facilities (for children with developmental disabilities), or the disease-specific comprehensive care programs (such as those for children with hemophilia). The following recommendations have been implemented in part in several areas of the country. The Vanderbilt project sees them as key elements to incremental improvements in services for chronically ill children and their families.

- Regional data systems should be developed, broadly incorporating information on a) populations and children in need of services, b) services provided, and c) regional resources for chronically ill children. Data should reflect medical and surgical care along with

other services including educational, genetic, psychological and nutritional care. Such data should lead to the development of regional plans for chronically ill children, permit identification of major gaps in services, and allow monitoring of the effects of program changes.

.The Scope of Services for each service agency should be explicitly defined and when taken together available services should be broad enough to meet the large variety of family needs resulting from chronic illness in a child.

.Individual Service Plans should be developed (and periodically monitored) for each chronically ill child. Plans should attend to main realms affected by chronic illness or otherwise important to the progress of the child, including medical-surgical, developmental, educational, and family. Although all services will rarely be carried out by any one provider, the plan should carefully allocate responsibilities for each service to a specific provider. Otherwise, a needed service may be omitted by several providers, each believing another is responsible for the service.

.Maintenance of the strengths of specialized care centers is essential to assuring quality technological services. These centers, usually in academic health centers, need protection from potentially negative impact of new competitive financing proposals.

.Greater responsibilities for primary providers in the care of chronically ill children should be encouraged. Primary pro-

viders are usually closer to families than are specialists both geographically and in the sense of knowing the families. Although some are reluctant to assume added responsibilities of working with families with chronically ill children, many provide excellent treatment, care coordination, and family support. The role of primary providers will be enhanced by a) more equitable reimbursement for time invested in complex family and illness problems, b) effective continuing education, and c) improved regional communication systems emphasizing easy transfer of information among different providers.

.Case coordination is critical to improving services for chronically ill children and their families. Coordination is a function which can be carried out by any of a number of people, including nurses, social workers, pediatricians, and lay counselors. That the function be carried out is far more important than who does it. Effective care coordination will improve the functional outcome for the child and family and may cut down on unnecessary utilization of expensive health services. The importance of care coordination should be recognized by reasonable reimbursement for the service.

.Implementation of the recommendations to improve organization of services can come through a targeted project grant program to agencies. Eligible applicants could include academic health centers, state or local C.C.S. agencies, developmental disabilities programs (including UAF's) among others.

Financing of Services

Most proposed changes in health care financing attempt to meet varying and sometimes competing policy goals: assuring that citizens have access to basic health care, assuring that ruinous cost is not incurred, and at the same time controlling the costs and expenditures in the health care sector. Principles to guide consideration of new financing proposals follow, with comments on important aspects of both proposed and current financing programs as they affect chronically ill children and their families. Policy should recognize that chronicity means a financial outlay year after year, not just for acute episodes which typify most childhood illnesses; the high cumulative expenses can ruin families financially. All families with severely chronically ill children require access to financing of a broad range of services, regardless of the parents' employment or economic status.

.Implications for private health insurance programs based on fee-for-service are:

-Access to the relatively broad and deep coverage of group policies is linked to employment, mainly in large firms. Some of the remedies for exclusion from group insurance policies that could benefit many chronically ill children and their families include extension of coverage to low-wage or seasonal employees, conversion privileges from group to individual policies, and mandatory coverage of dependents in family policies. Conversion privileges

for dependent children would be especially helpful to chronically ill children who reach the age at which they are no longer covered by their parents' policies. Several states have mandated high risk pools, in which all insurers in a state share the risks for uninsurable persons; high risk pools can provide protection to chronically ill children and their families although they entail high annual out-of-pocket expenditures for premiums, deductibles and co-insurance.

-Because most insurance plans are oriented to high-cost hospital inpatient care, they tend to cover only medical services or ones offered under the direction of a physician. They seldom contain incentives to preventive and primary care, nor do they cover the broad range of special services and materials -- outpatient drugs, tests, and so on -- that are essential for chronically ill children. Fee-for-service insurance systems need encouragement to provide coverage of a different mix of services, as some are now doing (e.g., recent experimentation with coverage of home care as an alternative to hospitalization). Coverage of ambulatory services, rehabilitation and health education would improve the care of chronically ill children and might prevent costly hospitalizations.

-Insurance through prepaid group practices rather than fee-for-service might provide a broader mix of services, contain aggregate health care costs, and protect families financially. Ac-

cess to the highly specialized care needed by many chronically ill children needs to be assured in capitation programs.

.Implications for catastrophic health insurance, proposed in a number of forms in recent years as the preferred form of national health insurance, include:

-Catastrophic health insurance is criticized frequently for causing reallocation of health resources away from preventive care to higher cost care, hospitalization, and other services that already receive disproportionate coverage. However, properly structured, catastrophic insurance could provide valuable protection to chronically ill children and their families.

-Catastrophic health insurance plans have tended to address the costs of a catastrophic event rather than solving the equally serious problem of expensive chronic illnesses. For example, most plans provide reimbursement only after 60 days of hospitalization in a year, a benefit that excludes the large number of chronically ill children whose days in the hospital may be fewer per year, but whose hospitalizations recur frequently. In addition, most of the proposed plans do not provide reimbursement for outpatient drugs, often necessary in large and costly quantities for chronically ill children. An alternative provision would be to apply all major medical expenses toward a single deductible amount.

-The enormous financial burden on families of children with chronic

illnesses is not reflected in calculating only one year's expenses. The large expenses persist year after year. Most catastrophic insurance proposals are directed to cushioning a family against having savings wiped out by a single event. An alternative policy would be longer deductible periods, of perhaps several years.

-An income-based deductible which limits expenditures on medical care to 10-15% of income would be especially important for young adults with severe chronic illnesses. These young people frequently are unable to retain full-time employment, yet they do not qualify for Medicaid. Income-related insurance protection would make a great difference in access to care and financial independence.

.Some implications for competitive proposals include:

-Most competition proposals are likely to cluster users of many services and therefore of high cost care in the higher cost plans. "Adverse selection" could price the higher benefit plans needed by chronically ill children out of their reach. Methods to share the risk need to be included in competition plans.

-Competition plans place limits on the percent of income or the flat dollar amount the individuals must pay out-of-pocket for health care before the insurance plan pays for care. However, the narrow definition of eligible services and their defini-

tion as related to a "spell of illness" means that many services used by chronically ill children are not counted in the deductible. To meet the needs of chronically ill children, the deductible should take into account all the out-of-pocket medical expenses and the price paid for insurance premiums, and be based on a reasonable percentage of income rather than a flat dollar amount.

-Competition approaches or the removal of tax exemptions for insurance premiums could result in more circumscribed plans. In sum, these approaches must be designed very carefully so as not to isolate families with predictably high medical care costs, making it more difficult for them to find adequate coverage.

.Some implications for government funded programs:

-Medicaid has unquestionably made a significant contribution to the care of chronically ill children by financing hospital and outpatient benefits previously not available. The uneven pattern of eligibility and benefits among the states is exacerbated by the cuts in funding in recent years. Further such reductions will only harm further poor chronically ill children and their families. Cost containment through medicaid capitation plans, use of home-based care to substitute for hospitalization, and other administrative rearrangements are vastly preferable to reductions of eligibility and benefits.

-Crippled Children's programs finance a wide range of inpatient and outpatient services through various arrangements. Each state has a unique service profile and wide discretion in selecting the conditions to be treated. Maintaining the funding level of the CCS program within the Maternal and Child Health Block Grant is of great importance to chronically ill children, in light of the special services for these children the CCS provides. Modification of CCS in the direction of the proposed Regionalized Program for Chronically Ill Children and their Families would distribute CCS benefits more effectively and equitably.

Schools

.The chronically ill child whose condition only mildly or infrequently affects schooling -- children who occasionally require medications or who need modified gym classes -- are most appropriately served by the regular education system, utilizing counseling and school health services. To insure that the chronically ill child with a mild impairment receives the necessary services within each school district, each state should adopt explicit school health codes for chronically ill children and mandate adoption by local school systems. Codes should include policies and procedures at least in the following areas: medication procedures, case registry, emergencies, in-service training, and case coordination.

.Special education, as defined in P.L. 94-142, should not be extended,

or stretched, for the purpose of including nonhandicapped children who are in need of "related services." However, the related services portion of that law should be revised (or separated in law) to require the provision of related services to all children, handicapped or not, if essential for children to participate effectively in an appropriate education program in the least restrictive environment.

- More flexible policies regarding the use of homebound and hospital instruction should be adopted. The consecutive absence period necessary currently to qualify for homebound services results in many chronically ill children going without important instructional services.
- Schools must adopt internal policies for coordinating regular education and special education. These educational entities should not remain separate service delivery systems with different technologies and goals. In the event related services are made available to children based upon need, the three sections must interact on a regular basis.
- Training within the school regarding chronically ill children, and efforts to educate and sensitize should be directed at both school personnel and other students. School personnel should receive training related to a child's specific condition under the direction of a school nurse or physician. Specific curricula or techniques to explore and modify student and teacher attitudes about chronically

ill children should be developed. Supportive personal counseling may be required for school personnel involved with the education of children with terminal or progressive illness.

.Schools must have health related information about chronically ill children for proper placement and programming to occur. Appropriate functions for the physician are the transfer of information to the schools and the fostering of two-way communication between schools and physicians. In general, the physician's role as a consultant rather than an educational decision-maker needs clarification.

Research

.Support for basic biomedical research, via the mechanism of the NIH, should remain a very high priority.

.The investment in basic biomedical research should be balanced with an equally vigorous commitment to basic research in other critical areas, including behavioral sciences and health services research.

.A number of areas appear especially promising, for example, in primary prevention of handicapping conditions and in improving the process of childhood coping with chronic illness. Support for basic research in genetics, in the development of certain new technologies (such as the insulin pump for diabetes), in epidemiology, and in family coping and adjustment merit special attention.

.Several arguments mitigate against the study of illness only among

patients appearing in teaching centers for tertiary care hospitals. Population-based studies of chronic childhood illness are essential to understanding the diseases, their onset, ramifications, and treatment.

.Given the relative infrequency of many chronic childhood illnesses, adequate numbers of children with any specific disease may not be found in a single center. Interinstitutional research should be fostered and supported.

.Successful collaboration among different biomedical disciplines should be expanded to stimulate joint research ventures among such disciplines as psychology and medicine, physiology and nutritional sciences, nurse-researchers and pediatrics.

.Support for the training of scientists, especially from the clinical disciplines, to develop strong quantitative and data management skills and incorporate the tremendous expanding knowledge in the field of clinical epidemiology, needs expansion.

.Much basic research in child development has come recently from the area of developmental disabilities, often with support from the National Institute of Child Health and Human Development. The skills and developmental knowledge arising from this research have major implications for chronic illnesses in childhood as well and should be creatively applied to this area.

.Recent efforts to clarify the ethical considerations in research on children are commendable and outline an area of fruitful future

investigation. Though the balance between ethical pursuits of new knowledge and preservation of the rights of children may be difficult to achieve, inattention to the problem may lead to potentially dangerous and unproven therapies applied haphazardly to children.

.The benefits of research should find timely application in service programs for children and families. The development of regional, integrated programs for chronically ill children will improve the daily interaction between those doing basic research and those providing varied levels of service.

Training of Providers

.Increased attention to the problems of childhood chronic illness is needed in all health professional schools. Training should emphasize:

-longitudinal experience with the families of chronically ill children, during both acute and quiescent phases,

-collaboration among disciplines in working with families, and

-a broad definition and approach to child and family needs.

.Concepts in the care of children with chronic handicaps are applicable to several other realms, such as geriatrics or substance abuse. Special emphasis is needed in professional schools on concepts from clinical epidemiology, patterns of human adaptation, ethical decision making in long-term care and principles of patient management (distinguished from disease cure).

.Training in the family and developmental impact of chronic childhood illness is important for specialists and generalists alike. Trainees need skill not only in dealing with disease processes, but also a firm understanding of the influences of genetic, familial, environmental, and social factors on chronic illness in children.

.Basic understanding of nutritional concepts, psychological precepts and educational issues (both to promote healthier behavior and to work effectively with schools) are essential for the training of involved health professionals.

.A few exemplary training programs in chronic childhood illness should be developed. These should be interdisciplinary in faculty and in trainees and should have the goals of producing both new researchers in the broad area of chronic childhood illness and other graduates able to provide leadership to public programs for children with handicaps. Unlike most present programs housed in schools of public health, the new training programs will be based within academic health centers, probably in the context of organized regional programs for families with chronically ill children.

.Faculties of nursing, medicine, and related fields should expand attention to the generic problems of chronically ill children by adding new members expert in these problems, likely graduates of the training programs above.

.Training for research careers, both in disease-specific areas and in chronic illness in general, remains a high priority. There is con-

tinuing and indeed increasing need for researchers well-grounded in quantitative skills and methodologic principles, and with good backgrounds in theory applicable to the problems of sick children. Yet opportunities for research training in chronic illnesses of childhood, outside of specialty fellowships for pediatricians, are limited, especially in nursing and psychology. New interdisciplinary training programs will fill an important gap.

Continuing education for child health providers should address issues in early identification and referral of chronically ill children, new developments in management of chronic illnesses, aspects of care coordination, and advances in understanding of family coping and adaptation.